

Belonging Matters' Podcast

Transcript

Episode 9: Getting on with Life: How we built and Inclusive Life with Alex

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Welcome to Belonging Matters podcast series. Now available on Apple podcasts, Google podcasts, Spotify, and www.belongingmatters.org. Episode Nine, Getting on with Life: How we built and Inclusive Life with Alex. Bridget leads the paradigm initiative, a small agency based in Auckland that was established in 2011 to walk alongside and assist families in creating and sustaining good lives for their family member with a disability. She has also been actively involved in the disability sector for over 20 years in a variety of roles. The mother of three, her eldest son, Alex has an intellectual disability and with her husband has encouraged his individual autonomy, self determination and dreams. This has been the result of his family having a lifetime commitment to his full social inclusion and the vision that his life would reflect that of his siblings. In

this podcast, Bridgette explains how Alex lives in his own home and leads a fulfilling life as a valued member and contributor to his community.

In the early 1990s, it was my good fortune to have attended a workshop with the late Marshall forest. And Jack P. Point presented on inclusion in something that was said has remained with me the criteria for being included breathing with a respirator if you need one. With this little nugget, my husband and I forged ahead with an absolute commitment to making sure that our son Alex, was to have a life similar to that of his siblings. Although Alex has Down syndrome, we never let this define who he is. Alex has lived played and me been educated alongside his neighbours and peers. Sounds easy, but rest assured, there were times when we had to fight hard to ensure his full inclusion in all aspects of life. As parents, we just wanted them to be treated the same as others, but at the same time asking that some leeway was given to take into account that he has an intellectual disability. What didn't break us made us stronger and even more determined to craft a good life for Alex. Somehow, we managed to remain focused on the long term vision we held for our family. And in particular, for Alex, we wanted Alex to enjoy the things in life that siblings would take for granted to be independent of us, non participate in the world around him, walk with his head held high, and become a man with confidence, who has an understanding and acceptance of himself will also meant for Alex to have valued roles doing whatever it was, that had meaning to him. Throughout his life, there are many examples of where Alex has just been another person in the group to where he is being

singled out and isolated from the group. If Alex was to have a similar life to his brother, then we had to be very clear and committed to what it was we were wanting for him. Every decision we made from very early in life was going to have an impact on the next decision and ultimately his future. So we were intentional with everything we did with him for Alex. Today, Alex is living the life on his terms. He is reasonably well connected to his local community is actively involved in his church, plays sport has well established portfolio work, and, most importantly of all, he has a wonderful group of family and friends who love him. Alex has meaning in his life enjoys what he does on a daily basis, and feels valued by those around him. When Alex was about 15 years old, it became evident that he was lonely, isolated, and struggling to keep up with school, both academically and socially. Our other son was feeling overwhelmed with what he saw going on at school and we were almost always and therefore mode. Life was in crisis. So we knew we had to take positive action. Has it been introduced to the sibling support concept? We decided that this could be a strategy that would work for us. the very least we had much to gain and nothing to lose. We quickly became clear on what the purpose of bringing people together in this way Will was to ensure Alex was not isolated and lonely at school, and that he continued to receive a good education.

With a purpose in mind, we then said about bringing people together that we knew who had an understanding of the education system, people who loved and cared about Alex and his family, we wanted people who understood and supported our long term vision for Alex. Their circle of support was to

become known as Alex's champions, which is exactly what they were. They were his champions in his corner and had our back, we were confident that they would keep the vision for Alex alive if we were to die. The people we invited to join us in our journey with Alex were friends, some clothes, some old school principal and a young man who had previously been employed to sport Alex. Indu wanted to stay in his life. No one was paid to be on the circle, and they didn't have paid roles in our lives. When Alex was preparing to leave home, this first circle of support was redundant after an eight year commitment, because the purpose had changed. And it was now very appropriate that young people came together in support of Alex. The young chimp's be meeting regularly for nearly two years, and are there to help make life good for Alex and to make sure he does not become like isolated and lonely as he forges ahead with his own life. Alex holds a portfolio of work, which was put together over about a two year period, and was part of the planning that happened once he leaves school, he was very clear that he wanted a job helping people. He held aspirations to be a position and to work in an office like as dead, he wanted to be his own boss. His circle of support was an active part of the process of listening to this, and we all knew it was up to us to make these explorations into a reality for every Thursday, Alex works in the Auckland Catholic Diocese office, and has now been there almost six years. Alex is without question a considerable invaluable part of the administration, obtained by as co workers, over times co workers have began to see passes intellect from disability now view him as a work colleague, who is making a contribution to the running of the office. His parents, we found it too hard to go

cap in hand, and ask around for a job for Alex. We had already done this, we searched for a school. So doing it all again was just too much. This is where having the circle of support was tremendously helpful. As a member of the circle who put their hand up and did the asking to our delights. This strategy worked. And with confirmation that a roll would be created for Alex. He was then interviewed and the start date confirmed. job coaching needed to be arranged no theory that things came unstuck. It was a little surprised to find that the service provider contracted by government was not at all helpful. And it became apparent very quickly, that the job coach or the support person was actively keeping Alex separate from his colleagues, or reminded us of the teacher aid was attached like Velcro on a student. Not a good luck when you were a young man wanting to fit into the workplace. We knew something had to change and quickly. So with the support of Alex's manager was decided that we would employ someone that we knew and trusted to work alongside Alex and his employer. This was to help Alex get a good understanding of the role and expectations they employ ahead of them. We often knew that someone had to be available to answer any questions or concerns the employer head. This person was also the to ensure Alex did a good job, but also that his role grew over time. The aim of course was to make this person redundant, but only when we were confident that Alex is doing a good job. His role was very secure. And when his employer was confident and held high expectations of them, working in the Catholic Diocese office had a positive positive spin off for Alex and his local Catholic church.

And it seemed that he was viewed somewhat differently and had taken a little bit more seriously by fellow parishioners. Alex had been an altar server for many Yours in the younger children now looked up to him as a leader and teacher, really listening to what it was that Alex wanted has been very important, as well as putting aside personal pride to invite others into our life. Who would do the asking when we couldn't? Alex has been going to Seido Karate for coming up eight years, and as one would expect is very well known and respected by this tribe members. When he first joined, my husband phoned the club and was upfront on the person that answered the phone that our son has Down syndrome. And he was very keen to learn karate, Gary was told, Alex is most welcome to come and have a look and see if it was right for him. While the rest is history, we very intentionally remained in the background, we made sure that he was there as many lessons that we could manage in a week. And we checked regularly to see if he wanted to keep going. We also made sure we were available in case there were questions, however, little was asked. And they all just got on with teaching Alex gurashi. With the same respect, they treated all the other grad students was very heartwarming, when I learned that they were really pushing Alex to achieve and gave no room to slag off. They had the same expectations of him as they did of the others. I just had to learn to trust them to get on with that. And I did over time. Some of the critical aspects for long term success that I've found, the following has been what has worked for us and critical for long term success. Number one, having a vision for a good unordinary life, if we didn't have this, how would we have known what to compromise on having the circle of support?

Sometimes it's just too hard to do the asking, and so liberating, when you have the right people to ask for you, I learned that I had to learn to trust others, that they will do the right thing. by Alex. I often reflect on how we have got Alex to where he is now. And I know that one of the reasons is that we ask for help inactively put a circle of support around us when it got very tough. We have had net of signalled support in place for almost 10 years, the circle of support has been the most influential element and making life good for Alex was members of a circle who would do the asking, and it was the circle members who kept us focused on the big picture. They didn't let us sweat the small stuff, including Alex, to what people ordinarily take for granted, would have not been made possible without a vision for his future, and our absolute belief that he belonged alongside his peers, neighbours and friends, just because he breathed.

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